The pediatric penile perception score: an instrument for patient self-assessment and surgeon evaluation after hypospadias repair

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Abstract: PURPOSE: The aim of this study was to develop and evaluate an instrument that allows assessment and comparison of penile perception of patients, parents and surgeons. MATERIALS AND METHODS: A total of 77 boys 6 to 17 years old who had undergone hypospadias repair were interviewed by a psychologist with a standardized questionnaire concerning penile self-perception with regard to meatus, glans, skin and general appearance. The Pediatric Penile Perception Score was derived from the sum of these 4 items. The results were compared with a control group of age matched boys following inguinal hernia repair. Parents were asked via questionnaire to report the penile appearance of their son using the Pediatric Penile Perception Score. A total of 56 patients accepted standardized photographic documentation, and their pictures were sent for evaluation with the Pediatric Penile Perception Score to 6 blinded urologists. RESULTS: The Pediatric Penile Perception Score allowed us to assess perception of the genitalia by patients, parents and urologists. Statistical analysis of the Pediatric Penile Perception Score assigned by the urologist revealed good interrater reliability (interclass correlation 0.75 to 0.88) and stability (r = 0.59 to 0.83). Intercorrelation of the items "meatus," "glans" and "skin" with "general appearance" was good among the boys, parents and urologists. Patients with hypospadias expressed high satisfaction with the penile appearance, which did not differ significantly from age matched controls. However, parents and urologists were less satisfied with the penile appearance than were the patients themselves. CONCLUSIONS: The Pediatric Penile Perception Score is a reliable instrument to assess penile self-perception in children after hypospadias repair, and for appraisal of the surgical result by parents and uninvolved urologists.

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The Pediatric Penile Perception Score: An instrument for patient's self assessment and surgeon's evaluation after hypospadias repair

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Descriptive Runninghead
The Pediatric Penile Perception Score: Assessment after hypospadias repair

Key Words
Hypospadias, outcome assessment, child, surgery

Abstract

Purpose
The aim of this study is to develop and evaluate an instrument that allows to asses and compare the penile perception of patients, parents and surgeons.

Materials and Methods
Seventy-seven boys after hypospadias repair between the ages of 6-17 years were interviewed by a psychologist with a standardized questionnaire regarding their penile self-perception, including the following items: Meatus, glans, skin and general appearance. The Pediatric Penile Perception Score (PPPS) was calculated, consisting of the sum of these four items. The results were compared with a control group of age matched boys after inguinal hernia repair. A parent was asked with a questionnaire to report his son's penile appearance using the PPPS. Fifty-six patients accepted standardized photo documentation and their pictures were sent for evaluation with the PPPS to six blinded urologists.

Results
The PPPS allowed to assess perception of genitalia by patients, parents and urologists. Statistical analysis of the urologist's PPPS revealed a good interrater reliability (interclass correlation: 0.75-0.88) and stability (r=0.59-0.83). Intercorrelation of the items meatus, glans and skin with the general appearance was good in the boys, parents and urologists form. Hypospadias patients expressed a high satisfaction with their penile appearance that did not significantly differ from age matched controls. However, parents and urologists were less satisfied with the penile appearance than patients themselves.

Conclusions
The PPPS is an evaluated, reliable instrument to assess penile self perception in children after hypospadias repair and to appraise the surgical result by parents and non involved urologists.

Introduction

Recent progress in hypospadias surgery allows to achieve good cosmetic results, unimpaired sexual function and a normal micturition even for patients with proximal hypospadias. Yet, there is no perfect result and patients have to cope with minor cosmetic deficiencies such as scars.

Previous publications suggest that psychosexual function and quality of life in patients with distal hypospadias may be impaired [1,2]. However it is not clear, which factors influence this outcome and to which extent the surgical result contributes to it. Most likely, the perception of the genitalia by the patient himself is more important for the psychosexual development and the quality of life than the perception of the result by the urologist. The parent's attitude towards the child's genital appearance may potentially influence the child's own genital perception and development as well [3]. Therefore, instruments should be available to assess the penile perception of patients, parents and surgeons.

First attempts to compare patient's appraisal with the surgeon's assessment of the result were made by Schwobel et al [4]. In this study, the urologists themselves asked the patients for their evaluation of the surgical result and all patients reported a satisfactory or an excellent result. Mureau et al have improved the concept by developing a standard questionnaire consisting of 8 items about different aspects of the genitals. The total of the items, as rated by the patients, was compared to the rating given by a pediatric urologist who was not affiliated to the treating team. It was found, that patients were much less satisfied with the penile appearance than the surgeon 5. This standard assessment of single items by the patients was a big progress in the evaluation of results after hypospadias repair. Questions arise, however, whether the assessment of the outcome by the single urologist was objective. Baskin has introduced photographs, seeking to appraise the cosmetic outcome after hypospadias repair [6]. With a dual score, he evaluated whether the criteria overall appearance, mucosal collar, meatal location and configuration appeared as in a normal penis or not. This was the first attempt to systematically document the outcome of the penis after surgery based on the appearance. However, photos were evaluated by one reviewer only, the outcome by a person not involved in the treatment of the patient was not measured. Ververdis et al have assessed the cosmesis after hypospadias surgery with a scoring system that was based on photo documentation and presented to a panel of five independent health professionals [7]. Although the instrument was used successfully to demonstrate a different outcome between two surgical techniques, the quality of the instrument itself was not evaluated.

Because no comprehensive, reliable scoring system for penile perception has been published, we decided to develop an instrument and to evaluate it in a cross-sectional study. It incorporates some of the previous concepts to assess and compare the penile perception by patients, parents and surgeons.

Materials and Methods

Patients

147 boys and adolescents who were operated for hypospadias at the University Children's Hospital Zurich between 1991 and 2005 and who were between 6 and 17 years old at the onset of the study were eligible for this cross-sectional study. Exclusion criteria were genital surgery less than 12 months before the onset of the study, further planned operations for their hypospadias, chronic disease or other signs of a disorder of sexual development (DSD) besides the hypospadias. 102 patients fulfilled the recruitment criteria and 77 families agreed to participate and were interviewed by a psychologist (75%). 56 had a physical examination and photo documentation by a urologist. The number of patients with interviews is higher than the one with photo documentation because some parents and adolescents refused photographs. 48 patients had distal hypospadias, 26 had penile hypospadias and 3 had penoscrotal hypospadias. Since 2000 most cases were operated with the tubularized incised plate method whereas earlier, MAGPI and Mathieu repair were most popular for distal hypospadias. Two stage Bracka repairs, onlay and tubularized flaps were used for proximal hypospadias. Sixty-two percent (48/77 boys) had just one procedure, while 38% (29/77 boys) had a two stage repair or were reoperated for complications.

A control group with healthy boys operated for inguinal hernias at our institution was recruited. 131 families had to be contacted to recruit 77 boys matched for current age and age at surgery with the hypospadias patients. Control subjects did not significantly differ from the hypospadias group with regard to mean age at 1st operation (hypospadias: mean (SD) 3.01 (2.37) years, controls: mean (SD) 2.81 (2.77) years) current age (hypospadias: mean (SD) 11.03 (3.31) years, controls mean (SD) 11.34 (3.32) years), nationality or socioeconomic status, but they had fewer operations and were admitted to the hospital for fewer days. Only very few patients of the control group were circumcised as circumcision is not a tradition for the majority of the Swiss men.

The study was approved by the ethical committee of the University of Zurich.

Methods

All patients and controls were interviewed by a psychologist regarding their penile appearance. Perception of the following items was asked: Configuration and position of the meatus, configuration and appearance of the glans, appearance of the shaft skin and mucosal collar, penile axis as well as general penile appearance. Patients could express their satisfaction for every single item according to the following four point Likert scale ranging from very dissatisfied (0 points), dissatisfied (1 point), satisfied (2 points) to very satisfied (3 points) (appendix 1). The Pediatric Penile Perception Score (PPPS) was calculated by adding the scores of the items meatus, glans, shaft skin and general appearance.

Parents were not present during the children's interview. However, a parent was asked to fill out a questionnaire and to evaluate the appearance of their son's penis that included the same items and the same scale as the patient's form (appendix 2).

After the interview, boys with hypospadias were examined by a pediatric urologist who obtained photographs of the penis in four standardized views: Oblique, lateral, anteroposterior with the penis held against the abdominal wall and anteroposterior with the penis held up straight (appendix 3). No urological examination or photo documentation was performed for boys in the control group. The photo charts were

sent to and evaluated by six blinded urologists (2 American, 2 British, 2 Swiss urologists) of whom four were not affiliated to our hospital. In the set of 56 charts, 10 were included twice without forehand information of the urologists to assess the stability of the instrument. The urologists were asked to rate the photos according to the same criteria and with the same scale as the patients (appendix 3).

Statistical Analyses:
Intercorrelation of single items to general appearance as well as associations between the PPPS and medical characteristics were calculated with Spearman's rank correlation coefficients. For the urologist's evaluation, the stability of the PPPS-items and the PPPS total score were calculated with Spearman's rank correlation coefficients. Interrater reliability was calculated with interclass correlation coefficients (ICC). The results of the urologists were averaged to obtain an objective outcome measurement. Mann Whitney U-tests were used to test agreement in penile perception between patients, parents and surgeons.

Results

Patients after hypospadias repair expressed a high satisfaction for every single item of the penile perception scale with mean values between 2 (=satisfied) and 3 (=very satisfied). Statistical evaluation to assess the internal consistency with interclass correlation showed a good intercorrelation of the items meatus $r=0.45$ ($p=.00$), glans $r=0.6$ ($p=.00$) and shaft skin $r=0.59$ ($p=.00$) with the general appearance. Patient's satisfaction for the single items of the penile perception and the PPPS showed no statistically relevant difference when compared with the control group (table 1).

Parent's satisfaction with the appearance of their son's genitals after hypospadias repair was relatively high with a mean value slightly above 2 (=satisfied) for each item of the PPPS. However, comparison with the parents of the control group demonstrates, that parents of the hypospadias patients are less satisfied (table 2).

Urologists were most dissatisfied with the results achieved when evaluating the photo charts, as their mean results for all the items were below 2. Statistical evaluation of the instrument revealed a high interrater reliability between urologists when tested with the interclass correlation coefficient and a high stability of the instrument. Intercorrelation of the items meatus, glans and shaft skin with general appearance was good (table 3).

Comparison of the patient's self-perception, the penile perception of their parents and the perception of urologists shows striking differences. While parents' perception was only slightly but statistically significantly inferior than patient's self perception, the urologists considered the results much poorer than patients and parents (table 1 and 2).

In the interview of the patients and the control group, the item perception of the penile axis was included as well. However, when the results were controlled with the Spearman's rho test, the item had a poor intercorrelation with the general appearance for the patients ($r=0.28$, $p=.02$). Penile axis may be an important item after hypospadias repair, however, due to the conflicting self reported results and the

inability to judge the axis by an independent urologist on a photograph of the flaccid penis, we decided to omit the item for further evaluations.

No significant correlation between the severity of hypospadias and the PPPS, neither in the patient's self assessment (r=0.15, p=0.41), the urologist's evaluation (r=0.16, p=0.23), nor the parent's evaluation (r=0.154, p=0.23) could be found. The number of operations and the PPPS did not correlate for patient's self assessment (r=0.04, p=0.73) and parents (r=0.00, p=0.99) , however a correlation was found with the urologist's PPPS (r=0.34, p=0.01). Furthermore, patients and controls were asked for their satisfaction with penile size and a similar correlation of the satisfaction with penile size and the PPPS was found for both patients (r=0.55, p=.00) and controls r=0.52, p=0.00)**.**

Discussion

The patient's penile self-perception could be reliably assessed with the PPPS. The instrument proved to be practical to use and the good internal consistency is an indication for its reliability. However, the high patient's satisfaction that is similar to the one of the control group was not anticipated and contradicts some of the few publications available 5,8. Nevertheless, non participating patients (24.5%) may be particularly ashamed of their condition and their penile self perception may be less favourable so that the patients included in the study may possibly give an overly optimistic view. The good self-perception could reflect the improvement of surgical results that have been achieved with recent techniques. However, with regard to the parents and the urologist's evaluation, it seems to be unlikely that this is the sole reason and other causes must be considered. Mureau has published an extensive survey on patient's satisfaction after hypospadias repair with a similar study design and found that his patients were less satisfied with the penile appearance than the treating surgeons [5]. In that questionnaire, 3 out of 8 items were related to penile size and one to the appearance of the scrotum and testes, so that comparison to our results is difficult. Furthermore, Mureau included older patients from 9 to 18 years with a mean of 13.3 years. Despite an overall high satisfaction of our patients, young age is associated with a higher PPPS. This development suggests a higher expectation of the patients regarding their penile appearance in adolescence and confirms other studies [8,9]. Therefore we assume that the satisfaction with the genital self-perception of our patients will further decrease with higher age. It would be interesting to assess the self perception of the very young patients below the age of 6 years, who were excluded in our study. However, we do not believe that a child below that age is able to understand the various items that were measured and to judge the appearance of his penis. Satisfaction with the penile appearance during childhood is relevant as it is one of the potential factors that may influence the psychosexual development of boys and can potentially interfere with the health-related-quality-of-life of the patients even beyond childhood [10, 11].

Parents of hypospadias patients were less satisfied with the appearance of their son's genitals than the patients themselves or the parents of the control group. This may not only reflect the parental assessment of the penile appearance but may also be influenced by their fear or feelings of guilt regarding their son's penile

malformation. Furthermore, parents have other penises to compare to and know where their son started and hoped the final result would look like. This negative appraisal of the result may be relevant for the patients because the parent's attitude towards a malformation may be another factor that could possibly interact with a child's psychosexual development [3].

The evaluation by 6 blinded urologists of whom 4 were not affiliated to our hospital allowed us a sobering view of our results. For none of the four items of the questionnaire, a mean of 2, that corresponds to "satisfied", was achieved. However, the instrument proved to be reliable with a satisfactory interrater reliability, stability and intercorrelation to general appearance. Therefore, we assume that the results of the urologists can be considered as an objective evaluation. Compared to the low satisfaction of the penile appearance by the urologists, patient's self-perception was clearly superior. This contradicts previous studies, which demonstrated that urologists were more satisfied than patients 5,8. It is possible, that our results after hypospadias surgery are inferior to those of other centers. However, as Bracka has pointed out, the treating surgeon is always biased when judging his own work and current surgical fashion may influence judgment, once one is committed to a method of treatment 8. A urologist who is not associated to the treating team does not include his expectations as compared to the severity of the hypospadias in his judgment but compares the outcome with a normal penis. For future studies we strongly encourage urologists to ask colleagues who were not involved in the treatment of the patients to evaluate the results after hypospadias repair. "Non believers" of one's own preferred technique tend to be more objective than the colleagues who follow the same treatment strategies. Standardized photo-documentation is the key to an objective outcome measurement.

Limitations

The present study provides an instrument to assess the outcome after hypospadias repair that is easy to use, has a good reproducibility and is of clinical utility, elements that are critical for a scoring system [11]. Because it is an instrument to measure perception, the functional outcome is not included. However measurement of the urinary flow could be added as an objective functional parameter to supplement the PPPS. Another element that is important for sexual function and appearance is penile straightness. It clearly needs to be examined intraoperative with an artificial erection test, yet, later evaluation by an independent urologist is difficult. Penile axis cannot be determined on a flaccid penis, be it during examination or on photo documentation. However, only very few pediatric patients are willing or capable of demonstrating an erection for photo documentation. In our study, the self-reported perception of the penile axis by patients and the control group gave conflicting results and the intercorrelation with general appearance was poor, hence we have decided to omit this item from the PPPS. Nevertheless, we assume that penile axis could be incorporated in a questionnaire on penile self- perception of adults. The last point that needs to be addressed is penile size: We have decided not to include it in the PPPS, because it is not a factor that is amenable to hypospadias repair. This may account partly for the more favorable self appraisal of our patients and controls when compared with other studies. However, we have assessed penile size in the boys' interviews and have found a positive correlation of penile size and PPPS as well in the patient as in the control group.

Conclusions

The PPPS is an evaluated instrument to assess penile self-perception in children after hypospadias repair and to appraise the surgical result by parents and non-involved urologists. Its reliability and ease of use are two prerequisites to make the PPPS a possible standard instrument for cosmetic assessment after hypospadias repair. For future studies on hypospadias we strongly suggest the assessment of the results by non involved urologists, as their appraisal of the surgical result may diverge considerably from that of patients and parents.

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Legends

Table 1: Group comparison of hypospadias patients with control group for self perception and parent's perception of their son's genitals (Mann Whitney U-test).

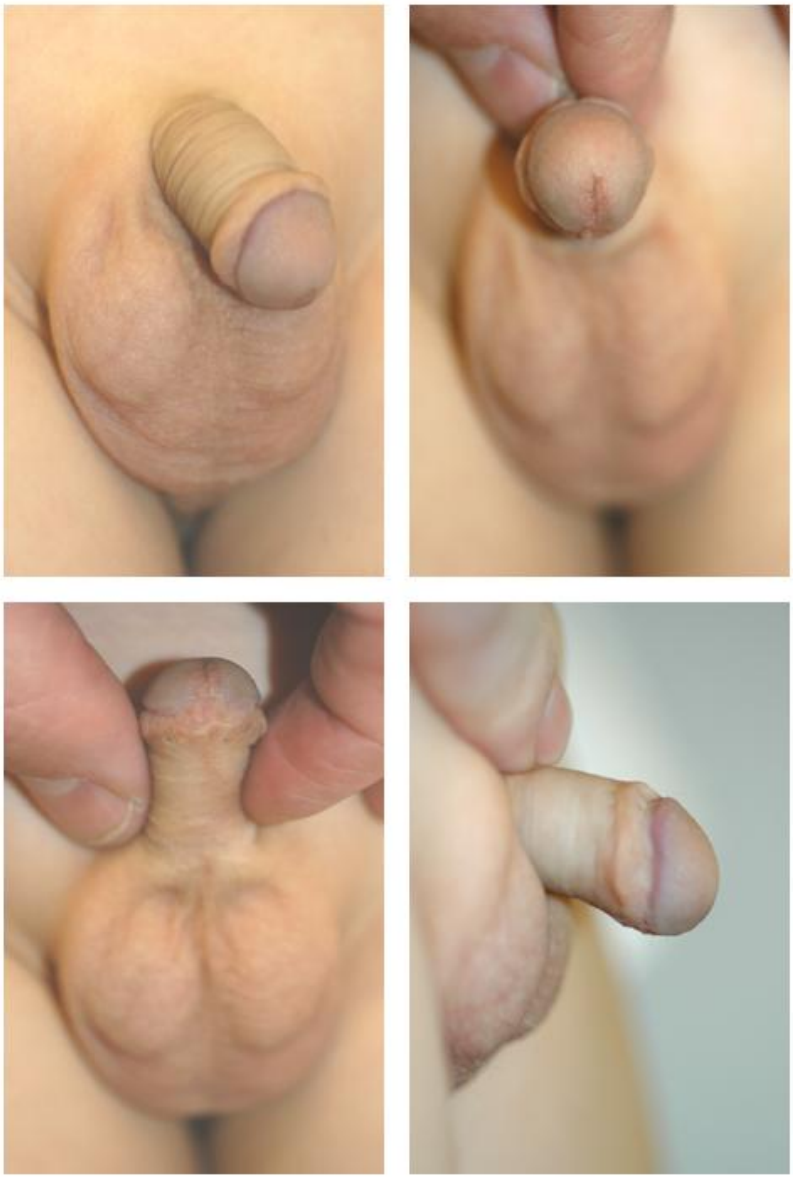
Table 2: Evaluation of patients by 6 blinded urologists: Mean with standard deviation, interrater reliability calculated with interclass correlation coefficients, stability and intercorrelation to general appearance (Spearman's rho correlation).

Appendix 1: Questionnaire for patients interview.

Appendix 2: Questionnaire for parents interview.

Appendix 3: Questionnaire for urologists including a photo chart with four standard views: Oblique, lateral, ap with the penis hold against the abdominal wall and ap with the penis hold up straight.

Patient 65 Rater:



GPS	very satisfied	satisfied	dissatisfied	very dissatisfied
Meatal position and shape	☐	☐	☐	☐
Shape of the glans	☐	☐	☐	☐
Shape of the penile skin	☐	☐	☐	☐
Penile axis	☐	☐	☐	☐
General cosmetic appearance	☐	☐	☐	☐

	Self perception Patients (SD)	*Self perception Control (SD)*	*p value*	*Parent's perception of patients (SD)*	*Parent's perception of controls (SD)*	*p value*
Meatus	2.50 (.64)	2.44 (.58)	.454	2.19 (0.70)	2.45 (0.50)	0.068
Glans	2.44 (.61)	2.44 (.61)	.995	2.26 (0.54)	2.48 (0.50)	0.051
Shaft Skin	2.44 (.57)	2.40 (.65)	.822	1.98 (0.80)	2.47 (0.54)	0.001
General Appearance	2.37 (.74)	2.49 (.70)	.337	2.13 (0.66)	2.47 (0.54)	0.010
PPPS	9.75 (1.95)	9.77 (1.97)	.935	8.54 (2.33)	9.86 (1.93)	.004

	Mean (SD)	*Interclass Correlation*	*Stability*	*Intercorrelation to general appearance*
Meatus	1.65 (.68)	0.88	0.74	0.45
Glans	1.84 (.50)	0.75	0.59	0.60
Shaft Skin	1.63 (.57)	0.78	0.69	0.59
General Appearance	1.64 (.57)	0.84	0.83	
PPPS	6.76 (2.04)	0.81	0.71	

	Patient's self perception (SD)	*Parent's perception (SD)*	*Urologist' perception (SD)*
Meatus	2.50 (.64)	2.19 (.070)	1.65 (.68)
Glans	2.44 (.61)	2.26 (.54)	1.84 * (.50)
Shaft Skin	2.44 (.57)	1.98 (.80)	1.63 * (.57)
General Appearance	2.37 (.74)	2.13 (.66)	1.64 * (.57)
PPPS	9.75 (1.95)	8.54 (2.33)	6.76 * (2.04)